

## Attention deficit hyperactivity disorder (update)

**[G] Evidence reviews for Adherence to treatment  
(pharmacological and non-pharmacological)**

*NICE guideline CG72*

*Evidence review*

*September 2017*

*Draft for Consultation*

*This evidence review was developed by  
the National Guideline Centre*



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# 1 Adherence to treatment (pharmacological and non-pharmacological)

## 1.1 Review question: What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD?

### 1.2 Introduction

Supporting adherence to treatment in people with ADHD has unique challenges. Non-adherence has been conceptualised as falling into two categories – intentional and unintentional (see NICE’s guideline on medicines adherence). Intentional non-adherence occurs when someone makes a decision not to follow the treatment recommendations and unintentional adherence happens when the individual is willing to follow an agreed treatment, but obstacles and problems beyond their control stop them from doing so. Non-adherence should not be seen as the person’s problem. It represents a fundamental limitation in the delivery of healthcare, often because of a failure to fully agree the prescription in the first place or to identify and provide the support that patients need later on. Given the difficulties people with ADHD may have with forgetfulness in everyday activities or in relation to organising tasks, they may be particularly prone to non-adherence of the non-intentional type. For example, they may plan to take their medication but forget to do so, or forget to fill the prescription, or lose the prescription in the interim between receiving it from their doctor and taking it to the chemist. In the case of non-pharmacological treatments they may forget when the appointment is or get distracted on the way to the session. The presence of co-existing mental health or neurodevelopmental conditions may also impact adherence.

The key principles of medicine management are well established and set out clearly in the NICE guideline on medicines adherence. These include ensuring people are involved in discussions about treatment and can make informed decisions about their care. While there are universal principles of care it is important that practitioners are aware of ways to support people with ADHD to be adherent to treatment plans and this chapter considers the factors that people with ADHD believe influence their adherence to both pharmacological and non-pharmacological treatment for their condition.

This review should be read alongside evidence report H on managing treatment and evidence report B on information and support.

### 1.3 Characteristics table

For full details see the review protocol in appendix A.

**Table 1: Characteristics of review question**

<b>Objective</b>	To investigate the factors that may affect adherence to treatment, so as to inform guidance to people with ADHD on receiving treatment
<b>Population and setting</b>	Children, young people and adults with ADHD who are receiving treatment (pharmacological or non-pharmacological) and their healthcare professionals, teachers, family and carers.
<b>Context</b>	Any themes that emerge relating to the adherence of treatment for people with ADHD
<b>Review strategy</b>	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient

qualitative evidence is identified

## 1.4 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual.<sup>142</sup> Methods specific to this review question are described in the review protocol in appendix A.

Declarations of interest were recorded according to NICE's 2014 conflicts of interest policy.

## 1.5 Qualitative evidence

### 1.5.1 Included studies

Fifteen qualitative studies were included in the review; Ahmed 2013<sup>1</sup>; Brinkman 2008<sup>14</sup>; Charach 2006<sup>27</sup>; Charach 2014<sup>29</sup>; Coletti 2012<sup>34</sup>; Gallichan 2008<sup>60</sup>; Ibrahim 2016<sup>88</sup>; Lefler 2016<sup>111</sup>; Matheson 2013<sup>125</sup>; Meaux 2006<sup>133</sup>; Meaux 2009<sup>132</sup>; Mills 2011<sup>135</sup>; O'Callaghan 2014<sup>144</sup>; Sikirica 2014<sup>164</sup>; Swift 2013<sup>178</sup> these are summarised in Table 2 below. Key themes from these studies are summarised in Section 1.5.2 below. See also the study selection flow chart in appendix C, study evidence tables in appendix D, and excluded studies lists in appendix G.

### 1.5.2 Excluded studies

See the excluded studies list in appendix G.

### 1.5.3 Summary of qualitative studies included in the evidence review

**Table 2: Summary of studies included in the review (pharmacological adherence)**

Study	Design	Population	Research aim	Setting
Ahmed 2013 <sup>1</sup>	Focus groups and a framework method of analysis.	16 parents of children with ADHD (aged 3 to 12 years)	To explore factors influencing parents' decisions to adhere and persists with ADHD medication	Australia
Brinkman 2008 <sup>14</sup>	Focus groups with open-ended questions and grounded theory analysis.	52 parents of children with ADHD (aged 6 to 17 years)	To explore how parents make decisions about treatment for their children with ADHD	USA
Charach 2006 <sup>27</sup>	Semi-structured focus groups and thematic analysis.	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)	To explore parents' attitudes towards medicating their child	Canada
Charach 2014 <sup>29</sup>	Semi-structured interviews and interpretive interactionist framework analysis	12 children with ADHD (aged 12 to 15 years)	Exploring young people's and parents' attitudes towards stimulant treatment	Canada
Coletti 2012 <sup>34</sup>	Semi-structured	27 parents of	To explore parent	USA

Study	Design	Population	Research aim	Setting
	focus groups and an inductive approach to analysis, using grounded theory.	children diagnosed with ADHD (aged 5 to 12 years)	perspectives on the decision to initiate medication treatment for ADHD	
Gallichan 2008 <sup>60</sup>	Open-ended interviews and grounded theory analysis.	12 young people with ADHD (aged 10 to 17 years)	Explore young peoples' perspectives of ADHD	UK
Ibrahim 2016 <sup>88</sup>	Semi-structured interviews and grounded theory analysis.	8 GPs, 8 consultants, 5 teachers and 5 mothers (of children and young people, age not specified)	Examine the experiences of drug holidays from caregivers and healthcare professionals	UK
Lefler 2016 <sup>111</sup>	Semi-structured focus groups and idiographic inductive analysis.	36 college students with ADHD (aged >18 years)	To explore the experiences of college students living with ADHD	USA
Matheson 2013 <sup>125</sup>	Semi structured interviews and thematic analysis.	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)	Explore adults experiences with ADHD	UK
Meaux 2006 <sup>133</sup> (Meaux 2009 <sup>132</sup> )	Semi-structured interviews and content analysis.	15 college students with ADHD (aged >18 years)	To gain insight about medication use among young people with ADHD	USA
Mills 2011 <sup>135</sup>	Semi-structured interviews and constant comparative analysis	19 families (representing 30 children with ADHD) (aged not specified)	To understand how parents decide to medicate their child	USA
O'Callaghan 2014 <sup>144</sup>	Semi-structured telephone interviews and thematic analysis.	18 adults with ADHD	To explore the context that influences stimulant medication adherence	USA
Sikirica 2014 <sup>164</sup>	Telephone interviews and thematic analysis.	38 caregivers (of ages 6 to 17 years) and 28 young people (13 to 17 years)	To explore the unmet needs of young people with ADHD and their caregivers	Mixed European countries (including UK)
Swift 2013 <sup>178</sup>	Semi-structured interviews and thematic analysis.	10 young adults with ADHD (aged 17-18)	Patient experiences of ADHD, particularly around transitioning	UK

Study	Design	Population	Research aim	Setting
			services	

1 **Table 3: Summary of studies included in the review (non-pharmacological adherence)**

Study	Design	Population	Research aim	Setting
Smith 2014 <sup>171</sup>	Semi-structured focus groups and thematic analysis.	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (aged Pre-schoolers). Parents were all undertaking group parent training	Understanding the reasons of low uptake and completion of parent interventions for ADHD	UK

2 See appendix D for full evidence tables.

3 **1.5.4 Qualitative evidence synthesis**

4 **Table 4: Review themes**

Main themes	Statement of theme
Understanding drug efficacy	Young people have a better understanding of the efficacy of their medication as they get older, and so adhere to it
Perceived benefit/lack of benefit	People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms.
Side effects	Side effects of medication were described as main reasons for not adhering to it.
Loss of identity	People reported that they didn't feel like themselves whilst on medication
Forgetting to take medication and time management	People with ADHD have difficulty remembering to take their medication and organising appointments.
Willingness to take medication	Children hide their medication from parents, or refuse to take it
Patient self-management	Young people and adults reduce their dosages or have drug holidays without consulting healthcare professionals.
Parental self-management	Parents reduce their child's dosage or have drug holidays without consulting healthcare professionals.
Difficulty accessing prescriptions	Adults report being unable to access treatment due to GPs or pharmacists refusing prescriptions.
Discontinuation when transitioning to adult services	Adults report long periods of treatment cessation when they are transferred to adult services
Barriers to treatments (non-pharmacological)	There are a range of psychological, situational and socioeconomic barriers to non-pharmacological treatment

#### 1 1.5.4.1 Narrative summary of review themes

##### 2 **Review theme 1: Understanding drug efficacy**

3 Young people felt that as they got older, they realised that their treatment was effective and  
4 useful for them. When they were younger, they made attempts to not take their medication,  
5 such as hiding their pills or refusing to take them. They gradually learned why they needed to  
6 take their medication, and so they adhered more to it as they got older.

7 Explanation of quality assessment: minor methodological limitations in the contributing  
8 studies; moderate concerns about coherence of the theme with review theme 7 showing  
9 conflicting results (patients making their own treatment plans without consulting healthcare  
10 professionals); partial concerns about applicability with one study being conducted in  
11 Canada, and the other in the UK; Moderate concerns about adequacy as data was not  
12 detailed. There was a judgement of moderate confidence in this theme due to the concerns  
13 regarding the applicability of the data and the adequacy

##### 14 **Review theme 2a: Perceived benefit/lack of benefit (pharmacological treatment)**

15 People on medication are more likely to adhere to their medication if they perceive it to be  
16 improving their symptoms. Parents are more likely to consistently adhere to treatment if they  
17 feel the improvements extend beyond ADHD symptoms, to functional improvements for all  
18 areas of their child's life, such as mood, sleep and social functioning. Adherence is also  
19 better when improvements from the medication outweighed side effect; when side effects are  
20 worse, this can lead to a lack of adherence. Young people also stop taking their medication if  
21 they don't feel like it is helping them.

22 Explanation of quality assessment: minor methodological limitations in the contributing  
23 studies; no concerns about coherence of the theme; partial concerns about applicability with  
24 only 2/6 studies conducted in the UK; no concerns about adequacy. There was a judgement  
25 of moderate confidence in this theme due to the concerns regarding the applicability of the  
26 data and the adequacy

##### 27 **Review theme 2b: Perceived benefit/lack of benefit (non-pharmacological treatment)**

28 Parents were more likely to drop out of parent training if they did not see improvement they  
29 expected quickly enough. This was combated by setting realistic expectations and in helping  
30 parents to see small improvements.

31 Explanation of quality assessment: minor methodological limitations in the contributing  
32 studies; no concerns about coherence of the theme; no concerns about applicability;  
33 moderate concerns about adequacy due to only one contributing study. There was a  
34 judgement of moderate confidence in this theme due to the concerns regarding adequacy of  
35 the data

##### 36 **Review theme 3: Side effects**

37 Adherence to medication is impacted by the level of side effects experienced by people with  
38 ADHD. Those that perceive a high level of side effects are less likely to adhere to their  
39 medication, especially if side effects are seen to outweigh the benefit gained from symptom  
40 improvement.

41 Explanation of quality assessment: minor methodological limitations in the contributing  
42 studies; no concerns about coherence of the theme; partial concerns about applicability due  
43 to only 1 of the 3 studies being conducted in the UK; minor concerns about adequacy, as  
44 data was not rich but had moderate quantity. There was a judgement of moderate confidence  
45 in this theme due to the concerns regarding the relevance of the data.

##### 46 **Review theme 4: Loss of identity**

1 Adherence to medication is affected by a loss of 'sense of self' in young people. They felt  
2 that the medication changed their identity by affecting their personality and the way in which  
3 they interact with the world around them.

4 Explanation of quality assessment: minor methodological limitations in the contributing  
5 studies; no concerns about coherence of the theme; partial concerns about applicability due  
6 to one study being conducted in Canada and one in the UK; moderate concerns about  
7 adequacy due to only two contributing studies, with limitations around data richness. There  
8 was a judgement of low confidence in this theme due to the concerns regarding the  
9 relevance and adequacy of the data.

#### 10 **Review theme 5: Forgetting to take medication and time management**

11 People with ADHD do not feel equipped to successfully stick to their treatment plan. They  
12 can forget to take their medication, which is a problem that impacts on their adherence to  
13 treatment. In addition they feel unable to keep monthly appointments for medication  
14 management. Parents often support their child by ensuring they take their medication, and by  
15 organising their appointments for them.

16 Explanation of quality assessment: moderate methodological limitations in the contributing  
17 studies (many limitations within the studies, such as issues with richness of the data, and  
18 details provided about data analysis, data collection, and the role of the researcher. No  
19 concerns about coherence of the theme; partial concerns about applicability; minor concerns  
20 about adequacy. There was a judgement of low confidence in this theme due to the concerns  
21 regarding the methodological limitations of the data and concerns about applicability.

#### 22 **Review theme 6: Willingness to take medication**

23 It can be difficult to give ADHD medication to children. Some children attempt to not take  
24 their medication by hiding it from their parents, and actively fight to not take their medication.  
25 This can make it difficult for parents to ensure their children adhere to treatment.

26 Explanation of quality assessment: minor methodological limitations in the contributing  
27 studies; no concerns about coherence of the theme; partial concerns about applicability (one  
28 study conducted in the UK, one in Canada); moderate concerns about adequacy due to only  
29 2 contributing studies. There was a judgement of moderate confidence in this theme due to  
30 the concerns regarding the adequacy of the data and concerns about applicability.

#### 31 **Review theme 7: Patient self-management**

32 People with ADHD sometimes take their medication at their own direction, without consulting  
33 healthcare professionals. They take 'drug holidays' depending on when they feel they need  
34 to take their medication, and when they don't. This is mainly for work or education purposes,  
35 such as periods of high work-load and exams. Others reduce their dosage or do not take  
36 their medication on the weekend because they don't want the effects of the treatment over  
37 this time.

38 Explanation of quality assessment: minor methodological limitations in the contributing  
39 studies; no concerns about coherence of the theme; partial concerns about applicability (one  
40 study in the UK, three in the USA); no concerns about adequacy. There was a judgement of  
41 moderate confidence in this theme due to the concerns regarding the applicability of the  
42 data.

#### 43 **Review theme 8: Parental self-management**

44 Parents of children and young people with ADHD often felt solely responsible for managing  
45 and monitoring their child's medication. Some parents could cope with their children not  
46 taking medication out of school hours, and felt it important to do so due to their concerns  
47 about side effects and the long-term impacts of medicating their child. Other parents felt

1 unequipped to do this and so their children were more likely to fully adhere to treatment.  
2 Parents also modify dosages or utilising drug holidays of medication when they are concerns  
3 about side effects. Although some parents consulted healthcare professionals before doing  
4 so, others did not.

5 Explanation of quality assessment: minor methodological limitations in the contributing  
6 studies; no concerns about coherence of the theme; partial concerns about applicability (two  
7 studies in the UK, two in Australia and one in mixed countries); no concerns about adequacy.  
8 There was a judgement of moderate confidence in this theme due to the concerns regarding  
9 the applicability of the data.

#### 10 **Review theme 9: Difficulty accessing prescriptions**

11 Adults with ADHD reported healthcare professionals and pharmacists as barriers to their  
12 treatment. They sometimes reported difficulty in accessing repeat prescriptions due to  
13 pharmacists being unwilling to dispense the treatment, or GPs being unwilling to prescribe  
14 medication. These sometimes cause long periods of treatment cessation, lasting from days  
15 to years, which is highly distressing for patients.

16 Explanation of quality assessment: moderate methodological limitations in the contributing  
17 studies; no concerns about coherence of the theme; minor concerns about applicability; no  
18 concerns about adequacy. There was a judgement of moderate confidence in this theme due  
19 to the concerns regarding methodological limitations.

#### 20 **Review theme 10: discontinuation when transitioning to adult services**

21 People with ADHD reported long delays in transitions to adult services from child services.  
22 This sometimes resulted in discontinuation of support and as a result caused periods of  
23 treatment cessation.

24 Explanation of quality assessment: minor methodological limitations in the contributing  
25 studies; no concerns about coherence of the theme; no concerns about applicability;  
26 moderate concerns about adequacy (only one contributing study). There was a judgement of  
27 low confidence in this theme due to the concerns regarding adequacy of the data.

#### 28 **Review theme 11: barriers to adhering to services (non-pharmacological)**

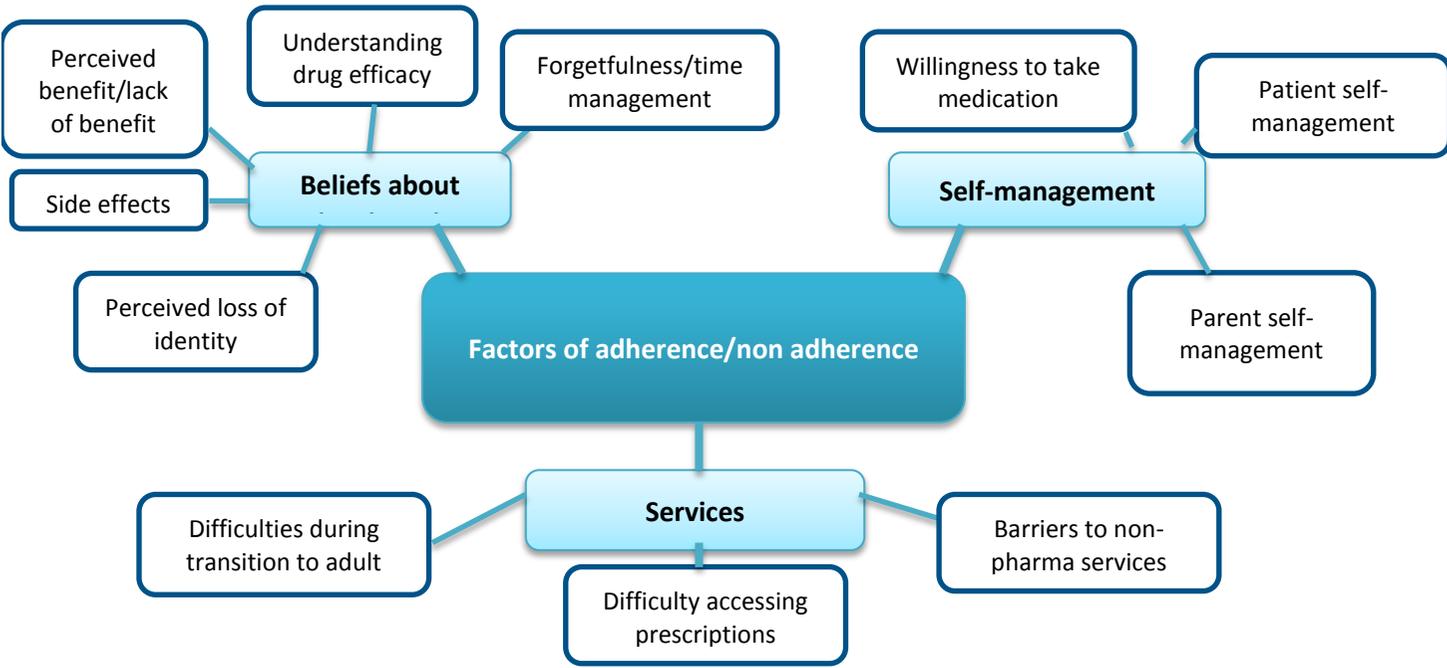
29 Many barriers for patients in accessing non-pharmacological treatment exist. Psychological  
30 barriers included feelings of shame, embarrassment and fear of being judged. Situational  
31 barriers included time commitments, inconvenient session times and location and child care  
32 issues. Practitioners also feel that a lack of education, cultural issues, domestic violence and  
33 financial difficulties impacted on adherence.

34 Explanation of quality assessment: minor methodological limitations in the contributing study;  
35 no concerns about coherence of the theme; moderate concerns over applicability due to  
36 study being based only on group parent training interventions; moderate concerns about  
37 adequacy due to only one contributing study. There was a judgement of low confidence in  
38 this theme due to the concerns regarding adequacy of the data and applicability.

39

40

Figure 1: Diagram of review themes



1 **1.5.5 Qualitative evidence summary**

2 **1.5.5.1 Theme 1: Psychological factors**

3 **Table 5: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 1: understanding drug efficacy (young people)					
2	2 interviews  (1 UK; 1 Canada)	Young people have a better understanding of the efficacy of their medication as they get older, and so adhere to it	Limitations	minor limitations	LOW
			Coherence	moderate concerns about coherence	
			Relevance	partially relevant	
			Adequacy	Moderate concerns about adequacy	

4 **Table 6: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 2a: perceived benefit/lack of benefit (pharmacological; all age groups)					

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
5	1 Focus group 4 Interviews  (3 USA, 1 UK; 1 Canada)  (3 children, 2 young people, 1 adult)	People on medication are more likely to adhere to their medication if they perceive it to be improving their symptoms. People are less likely to adhere to their medication when they do not perceive a benefit	Limitations	Minor limitations	MODERATE
			Coherence	No concerns about coherence	
			Relevance	Partially relevant	
			Adequacy	No concerns about adequacy	

**Table 7: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 2b: perceived benefit/lack of benefit (non-pharmacological; pre-schoolers; parent training)					
1	Interviews  (UK)	Parents were more likely to drop out of parent training if they did not see improvement they expected quickly enough.	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

**Table 8: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 3: Side effects; all age groups					
3	2 interviews 1 focus group  (1 UK; 1 USA; 1 Canada)	Side effects of medication were described as a main reason for not adhering to it.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	partially applicable	
			Adequacy	no concerns about adequacy	

**Table 9: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 4: Loss of sense of self (young people)					
2	2 interviews  (1 UK; 1 Canada)	People reported that they didn't feel like themselves whilst on medication	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

**Table 10: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 5: Forgetting to take medication and time management (all age groups)					
4	3 interviews 1 focus group	People with ADHD have difficulty remembering to take their medication and organising appointments.	Limitations	moderate limitations	LOW
			Coherence	no concerns about	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
	(1 UK; 3 USA)			coherence	
			Relevance	Partially applicable	
			Adequacy	minor concerns about adequacy	

1

2

3

1.5.5.2 Theme 2: Self-management

Table 11: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 6: Willingness to take medication (children)					
2	1 interview 1 focus group  (1 UK; 1 Canada)	Children can actively fight to not take their medication, or hide their medication from their parents.	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
			Adequacy	moderate concerns about adequacy	

**Table 12: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 7: patient self-management (young people and adults)					
4	3 interviews 1 focus group  (1 UK; 3 USA)	Young people and adults reduce their dosages or have drug holidays without consulting healthcare professionals.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	partially applicable	
			Adequacy	no concerns about adequacy	

**Table 13: Summary of evidence**

Study design and sample size	Themes	Quality assessment
------------------------------	--------	--------------------

No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 8: Parent self-management (children and young people)					
5	3 interviews 2 focus groups  (2 UK; 2 Australia; 1 mixed European countries including the UK)	Parents reduce their child's dosages or utilise drug holidays without consulting healthcare professionals.	Limitations	minor limitations	MODERATE
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	no concerns about adequacy	

**Table 14: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 9: Difficulty accessing prescriptions (adults)					
3	3 interviews  (2 UK; 1 USA)	Adults report being unable to access treatment due to GPs or pharmacists refusing to write prescriptions or dispense medication.	Limitations	moderate limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	minor	

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
				concerns about adequacy	

1 1.5.5.3 Theme 3: Services

2 Table 15: Summary of evidence

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 10: Discontinuation when transitioning to adult services					
1	Interviews  (UK)	Adults report long periods of treatment cessation when they are transferred to adult services	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

**Table 16: Summary of evidence**

Study design and sample size		Themes	Quality assessment		
No of studies contributing to the theme	Design		Criteria	Rating	Overall assessment of confidence
Review theme 11: Barriers to non-pharmacological treatment					
1	Interviews  (UK)	Psychological barriers (feelings of shame, embarrassment and fear of being judged) Situational barriers (time commitments, inconvenient session times and location and child care issues) Socioeconomic barriers (lack of education, cultural issues, domestic violence and financial difficulties)	Limitations	minor limitations	LOW
			Coherence	no concerns about coherence	
			Relevance	Partially applicable	
			Adequacy	moderate concerns about adequacy	

1 **1.6 Economic evidence**

2 **1.6.1 Included studies**

3 No relevant health economic studies were identified.

4 **1.6.2 Excluded studies**

5 No health economic studies that were relevant to this question were excluded due to  
6 assessment of limited applicability or methodological limitations.

7 See also the health economic study selection flow chart in appendix E

1

## 2 **1.7 Resource impact**

3 We do not expect recommendations resulting from this review area to have a significant  
4 impact on resources.

## 5 **1.8 Evidence statements**

### 6 **1.8.1 Clinical evidence statements**

- 7
- See section 1.5.4.1

### 8 **1.8.2 Health economic evidence statements**

- 9
- No relevant economic evaluations were identified.

## 10 **1.9 Recommendations**

11 G1. Use this guideline with the NICE guideline on medicines adherence to improve the care  
12 for adults with ADHD. The principles also apply to children and young people.

13 G2. Be aware that the symptoms of ADHD may lead to people having difficulty adhering to  
14 treatment plans (for example, remembering to order and collect medication).

15 G3. Ensure that people are fully informed of the balance of risks and benefits of any  
16 treatment for ADHD and that problems with adherence are not due to misconceptions  
17 (for example, tell people that medication does not change personality).

18 G4. Encourage the person with ADHD to use the following strategies to support adherence to  
19 treatment:

- 20
- being responsible for their own health, including taking their medication as needed
  - 21 • following clear instructions about how to take the medication in picture or written  
22 format, which may include information on dose, duration, side effects, dosage  
23 schedule (the instructions should stay with the medication, for example, a sticker on  
24 the side of the packet)
  - 25 • using visual reminders to take medication regularly (for example, apps, alarms,  
26 clocks, pill dispensers, or notes on calendars or fridges)
  - 27 • taking medication as part of their daily routine (for example, before meals or after  
28 brushing teeth)
  - 29 • attending peer support groups (for both the person with ADHD and for the families  
30 and carers).

31 G5. Encourage parents and carers to oversee ADHD medication for children and young  
32 people.

### 33 **Supporting families in which a parent has ADHD**

34 G6. Think about the needs of a parent with ADHD, including whether they need extra support  
35 with organisational strategies to help a child with ADHD to take their medication as  
36 prescribed.

### 37 **Supporting adherence to non-pharmacological treatments**

1 G7. Support adherence to non-pharmacological treatments (for example, CBT) by discussing  
2 the following:

- 3 • the balance of risks and benefits (for example, how the treatment can have a positive  
4 effect on ADHD symptoms)
- 5 • the potential barriers to continuing treatment, including:
  - 6 ○ not being sure if it is making any difference
  - 7 ○ the time and organisational skills needed to commit to the treatment
  - 8 ○ the time that might be needed outside of the sessions (for example, to complete  
9 homework)
- 10 • strategies to deal with any identified barriers (for example, scheduling sessions to  
11 minimise inconvenience or seeking courses with child care provision)
- 12 • a possible effect of treatment being increased self-awareness and the challenging  
13 impact this may have on the person and the people around them
- 14 • the importance of long-term adherence beyond the duration of any initial programme  
15 (for example, by attending follow-up/refresher support to sustain learned strategies)

## 16 **1.10 Rationale and impact**

### 17 **1.10.1 Why the committee made the recommendations**

18 The evidence identified several factors that affect adherence to treatment and these were  
19 supported by the committee's own experience.

20 The evidence highlighted time management and forgetfulness as particular issues so the  
21 committee made a recommendation that healthcare professionals should be aware that  
22 people with ADHD may have problems remembering to order and collect medication. The  
23 committee provided examples of how healthcare professionals might encourage people to  
24 follow strategies that support adherence (for example, following clear instructions and using  
25 visual reminders).

26 A common worry about treatment is that it might change personality and the committee  
27 agreed that this could affect adherence to both medication and non-pharmacological  
28 treatments. Misconceptions about the effects of treatment and worries about side effects  
29 were common themes identified, and the committee agreed that it was important that  
30 healthcare professionals address these.

31 Evidence identified the influence people close to a person with ADHD can have on  
32 adherence. The committee agreed that it was important that while children and young people  
33 should take responsibility for their own health (including taking medication) parents and  
34 carers should oversee them. The committee discussed the difficulties in families where  
35 parents may also have ADHD and made a recommendation to remind healthcare  
36 professionals that these families may need extra support.

37 The committee discussed that adherence to non-pharmacological treatment was an  
38 important issue that was rarely addressed. They used their own experience to recommend  
39 that healthcare professionals discuss the commitment, time and organisational skills needed  
40 for successful adherence to non-pharmacological treatment.

### 41 **1.10.2 Why we need recommendations on this topic**

42 Supporting adherence to treatment in people with ADHD has unique challenges. Given the  
43 difficulties people with ADHD may have with forgetfulness in everyday activities or in relation  
44 to organising tasks, they may be particularly prone to non-adherence of the non-intentional  
45 type. For example, they may plan to take their medication but forget to do so, or forget to fill

1 the prescription, or lose the prescription between receiving it from their doctor and taking it to  
2 the chemist. While the key principles of medicine management are well established and set  
3 out clearly in the NICE guideline on medicines adherence it is important that practitioners are  
4 aware of ways to support people with ADHD to be adherent to treatment plans and this  
5 chapter/ section considers the factors that people with ADHD believe influence their  
6 adherence to both pharmacological and non-pharmacological treatment for their condition.

### 7 **1.10.3 Impact of the recommendations on practice**

8 The committee noted that the recommendations will reinforce current best practice.

## 9 **1.11 The committee's discussion of the evidence**

### 10 **1.11.1 Interpreting the evidence**

#### 11 **1.11.1.1 The quality of the evidence**

12 All the evidence was of low to moderate quality. The majority of subthemes had minor  
13 methodological limitations in the contributing studies. There were mainly only minor concerns  
14 about the coherence of the themes. Many of the studies had moderate concerns about  
15 relevance and adequacy. The studies were all conducted in a population of people with  
16 ADHD, or in carers or healthcare professionals who supported people with ADHD. For some  
17 subthemes, only a small amount of evidence was identified. The majority of studies were  
18 conducted within Canada, the USA, Australia and the UK. Although Canada and Australia  
19 have similar healthcare systems to the UK, the USA does not. This was taken into account  
20 when assessing the applicability of the themes around the delivery of services. The  
21 committee were in agreement that the subthemes presented were consistent with their own  
22 clinical experiences.

#### 23 **1.11.1.2 Themes identified in the evidence synthesis**

24 The review identified a number of factors that influence adherence to pharmacological  
25 treatment in people with ADHD. These included psychological factors, self-management  
26 behaviours, and service barriers.

27 The perception of the benefit of treatment and side effects were found to influence  
28 adherence. People were found not to adhere to treatment if they did not perceive it to be  
29 improving their symptoms. Parents were also more likely to adhere to treatment if they felt  
30 the improvements extended beyond ADHD symptoms, to functional improvements for all  
31 areas of their child's life, such as mood, sleep and social functioning. In addition, adherence  
32 was found to be better when improvements from the medication outweighed side effects;  
33 when side effects were worse, this led to a lack of adherence.

34 The committee agreed that healthcare professionals should discuss with children, young  
35 people and adults with ADHD and their parents or carers the impact that medication can  
36 have on individuals, and how this can be managed. In addition, the committee noted that  
37 healthcare professionals should explain the process of achieving an optimal balance  
38 between efficacy of treatment and side effects, ways to reduce side effects (with particular  
39 emphasis on titration periods), the importance of adherence to treatment, and how parents or  
40 carers could help to improve treatment adherence. The committee noted that healthcare  
41 professionals should fully disclose possible side effects with people with ADHD and their  
42 carers. The committee also agreed that in young people and adults with ADHD, support  
43 groups could be a useful way for patients to gain support by discussing experiences with  
44 treatment with others. This evidence supported the recommendations made in the  
45 management of treatment and information and support sections.

1 The committee noted the importance of providing clear instructions, which should be  
2 individualized into the appropriate format for that person. They agreed that in families where  
3 parents or carers also have ADHD, healthcare professionals needed to be aware of the  
4 needs of parents and how they might require additional support to help their children adhere  
5 to treatment.

6 The committee discussed the monitoring of treatment, and agreed that healthcare  
7 professionals should endeavour to understand how the medication impacts the patients' life.  
8 They felt that in adults with ADHD, it may be useful to have someone else present during  
9 conversations.

10 Age was also found to influence adherence. Some people with ADHD began to understand  
11 why they needed to take medication as they got older, and so adhered to treatment. For  
12 others, they began to take control of their treatment and establish autonomy over decisions  
13 to take medication; in some cases only taking their medication when they felt they needed it,  
14 such as during times of high workload. The committee agreed that both of these  
15 circumstances arise, and they highlighted the importance of recognising young people's  
16 increased involvement in medication decision-making.

17 The evidence suggested that people were not adhering to treatment when they felt that it  
18 was causing a loss of identity or change in personality. The committee noted that they had  
19 often come across this in their own clinical experiences. They discussed the importance of  
20 healthcare professionals recognising these concerns, particularly in young people that have  
21 an increased autonomy over their medication decisions.

22 The evidence suggests that people with ADHD have difficulty remembering to take their  
23 treatment, and difficulty in arranging and organising appointments with healthcare  
24 professionals in order to monitor treatment. The committee discussed ways to reduce  
25 problems related to forgetting to take medication, such as obtaining batch prescriptions from  
26 pharmacies. The committee agreed that healthcare professionals should discuss techniques  
27 that could be used to support planning and management of medication taking. They noted  
28 that simple drug regimens should be used (for example, once daily modified release doses),  
29 in order to aid adherence.

30 The review identified barriers to services that are experienced by adults with ADHD. The  
31 evidence suggested that adults could find difficulty in accessing prescriptions, due to  
32 uncertainty from healthcare professionals and pharmacists. The committee discussed ways  
33 to improve these experiences for people with ADHD. They suggested that healthcare  
34 professionals should discuss these issues with people with ADHD. They agreed that people  
35 with ADHD providing documentation could help, which could be particularly useful when  
36 travelling abroad, as difficulty could arise due to carrying a control drug.

37 The evidence suggested that young adults may be unable to access treatment whilst they  
38 are transitioning from paediatric to adult services. The committee noted the importance of a  
39 shared care arrangement over primary and secondary care that could be continued at a time  
40 young people transition to adult services. They felt that this would improve the confidence of  
41 primary healthcare professionals in continuing to prescribe medication.

#### 42 **1.11.2 Cost effectiveness and resource use**

43 No economic evidence was identified on the adherence to treatment in people with ADHD,  
44 as this was a qualitative review and therefore did not look at the clinical effectiveness or cost  
45 effectiveness of interventions.

46 The recommendations made by the committee are not expected to have any major cost  
47 implications as they indicate what elements have to be considered by healthcare  
48 professionals in the discussion of treatment with the patients and all interventions that are  
49 mentioned are considered to already be best clinical practice. This review aims at changing

1 the content of discussions around treatment, rather than the quantity or intensity of the  
2 treatment reviews. Improved treatment adherence would lead to more efficient care and  
3 decision making further down the line with the aim of reducing treatment burden and adverse  
4 events, which would create some cost savings to the NHS.

### 5 **1.11.3 Other factors the committee took into account**

6 Based on their experience, the committee discussed what should be discussed between the  
7 person with ADHD, the parent or carer, and the healthcare professional. They felt that it  
8 should cover managing expectations of treatment and helping patients to understand the  
9 benefit and harm of treatment, and the impact on their lives as a whole. Healthcare  
10 professionals should relate this information to the importance of adherence to treatment. The  
11 titration process should be discussed, with particular emphasis on achieving an optimal  
12 balance between the efficacy and side effects of the treatment. The committee also felt that  
13 healthcare professionals should discuss with parents or carers issues around children hiding  
14 medication, or refusing to take it.

15 The committee also highlighted the importance of good communication and involvement of  
16 the child wherever possible, and for this to be appropriate to the developmental level of the  
17 child. They also emphasised the importance of individualising this for each patient or family,  
18 depending on their care needs. For example, the instructions should be in the appropriate  
19 format for that individual. This may be written instructions, instructions using pictures, or  
20 could use different methods based on the persons' needs, and appropriate to the  
21 development level of the person with ADHD. These discussions were based partly on their  
22 experience but also informed by the themes relating to the types of information people  
23 preferred. In addition, the committee noted that separate recommendations may be needed  
24 for families with ADHD, where the parents also have ADHD, or other behaviour or mental  
25 health conditions. Here, parents might need additional support in helping their children in  
26 adhering to their medication. This support should be individualised to the needs of both the  
27 parent and the child. There may be different communication issues that exist for children and  
28 adults, and so the committee felt recommendations should be made separately for each age  
29 strata.

30 The committee highlighted that providing immediate information on side effects was  
31 important, in order to give patients and their carers advice on what to do and how best to  
32 manage these. The committee highlighted that there may not currently be someone identified  
33 to do this, and that it is important to identify a specific healthcare professionals that could be  
34 contacted, in order to help with the optimization process. The committee highlighted that  
35 currently, services were discharging children back to their GPs, and GPs often do not provide  
36 the level of information on side effects that patients and their parents or carers require.

37 The committee highlighted that a shared care protocol was required to better equip GPs with  
38 the information needed to continue prescribing treatment. The committee noted that a  
39 number of the qualitative reviews in this guideline identified situations in which the interface  
40 between primary and secondary care was contributing to the variations in care. . The  
41 evidence showed that people with ADHD thought secondary services should be involved in  
42 distributing shared care plans. The committee felt that GPs had a responsibility of care to  
43 prescribe medication to people with ADHD, but had a lack of training or awareness in the  
44 area. Currently, some CDCs discharge young people with ADHD back to primary care before  
45 they transition to adult services, without full guidance on the treatment requirements  
46 necessary for the person with ADHD.

47 The committee highlighted that the needs of children and young people with ADHD could  
48 vary greatly, and that monitoring and managing adherence should take this into account.  
49 There could be a variety of responses to medication which relates to the child's increased  
50 role in decision making. For example sometimes, young people may need to stop their  
51 medication to understand the benefits they were receiving from it. The GC highlighted the

1 importance of 'watchful waiting' in these cases. Other children may be known to be lively and  
2 socially active. If their medication subdues them, they may be at risk of feeling like their  
3 medication has changed them too much to adhere to. The committee emphasised the  
4 importance of individualising treatment management and support to each persons' own  
5 situation.

6 The committee noted that in their experience shared decision making between the person  
7 with ADHD, the parents or carers, and the healthcare professional, could be difficult. Parents  
8 find their children's increased involvement difficult and the healthcare professional may find it  
9 difficult to determine the level of involvement from both patients and parents. The committee  
10 noted there should be clarity of what should be considered for children, young people and  
11 adults taking into the account the changing involvement of young people in their treatment.  
12 They noted that more involvement in decision making could occur from early on in  
13 adolescence and needs to be recognised by healthcare professionals. The committee felt it  
14 was important not to overlook the fact that they might need to give young people similar  
15 information to that they are giving adults.

16 The committee had concerns that the ADHD population may be more likely to be self-  
17 medicating and buying drugs illegally. In addition, they noted that some people with ADHD  
18 may be selling their medication and apparent adherence to treatment may be masking that  
19 the person with ADHD is selling on their medication. Issues around self-medication and  
20 selling of ADHD medication were identified in the review. The committee agreed that this is  
21 important for healthcare professionals to be aware of.

22 The committee discussed many ways to help people to remember to take their medication or  
23 order their next prescription. They highlighted the importance of clear instructions and the  
24 need for them to with the medication. This could be a sticker on the side of the packet, the  
25 committee noted that separate pieces of paper given at the same time as the prescription  
26 would be likely to be lost or forgotten.

27 Based on their own experience, the committee discussed the use of apps, and medicine  
28 boxes that use smart technology that will indicate whether or not you have taken your  
29 medication. For example, there are barcode scanning apps that will only allow a phone to be  
30 unlocked when the barcode on the medication has been scanned. The committee noted it  
31 would be useful to have a system in place to remind patients to reorder their medication  
32 when it's almost finished. Pharmacies can also be supportive obtaining repeat prescription  
33 from GPs, or access batch prescriptions which will help the person with ADHD to access  
34 treatment. They also noted other techniques to help planning, such as the use of dosset  
35 boxes so it is easy to tell how long ago the pill bottle was open, pill boxes should be labelled  
36 with days of the week. The committee were keen to illustrate the unique difficulties that  
37 people with ADHD have in adhering to medication and the story below, brought to the  
38 committee's attention by one of the lay members, reflects their experience and underpins the  
39 importance of these recommendations,

40 'Every morning the dreaded question: "Did I take my meds already?"

41 It is unavoidable no matter what trick I try to use.

42 This morning however the situation almost took a turn for the worse.

43 I was being my usual self, getting ready, making my lunch while putting on deodorant and  
44 checking reddit all at once, you know how it is.

45 Usually I stop when I see my pill bottle and have to wonder whether or not I've taken it, I  
46 realize I hadn't and take my medication out of the bottle. I then remember that I needed to  
47 give the dog her epilepsy meds as well, so I took her pill out the bottle. I then realized I didn't  
48 have the candy things they use to give her her meds, so I turn around to go to the cupboard  
49 and get them.

1 I get back to the counter, take a bite of my bagel, try to remember if the deodorant is out  
2 because I wanted to put it on or if I had just left it there. Anyways, grab the pill, put it in the  
3 candy thing for the dog, give it to the dog.

4 Did I take my meds yet?

5 Look on the counter, all that's there is the tiny epilepsy pill... oh no.

6 Chase the dog, grab the dog, get the stupid candy thing out of her mouth, break it open,  
7 there's my pill! Realize I would've killed the dog, get angry at myself, grab another candy  
8 thing give her the right pill.

9 Realise I'm gonna miss the bus, grab my lunch, out the door.

10 Get on the bus, wait... did I take my meds?'

11

12

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# Appendices

## Appendix A: Review protocols

**Table 17: Review protocol: Adherence to treatment (pharmacological and non-pharmacological)**

Field	Content
Review question	What factors do people with ADHD believe affect their adherence to pharmacological or non-pharmacological treatment for ADHD?
Type of review question	Qualitative
Objective of the review	To investigate the factors that may affect adherence to treatment, so as to inform guidance to people with ADHD on receiving treatment
Eligibility criteria – population / disease / condition / issue / domain	Children, young people and adults with ADHD who are receiving treatment (pharmacological or non-pharmacological) and their healthcare professionals, teachers, family and carers.  Stratify by age (<5 years old, 5 to 18, >18 years old) and treatment (pharmacological; non-pharmacological).
Eligibility criteria – intervention(s) / exposure(s) / prognostic factor(s)	Not applicable
Eligibility criteria – comparator(s) / control or reference (gold) standard	Not applicable
Outcomes and prioritisation	Themes will be identified from the papers, and not specified in advance. However relevant themes may include: <ul style="list-style-type: none"> <li>• Self-help tips to improve adherence; for example, use of alarms and reminders, use of technology/apps</li> <li>• Role of parents/partners/carers in promoting adherence</li> <li>• Psychological factors that impact on adherence; for example, self- and social-stigma, beliefs about ADHD and about treatment, comorbid mental health conditions</li> <li>• Dosing schedules, including use of extended release drug preparations</li> </ul>
Eligibility criteria – study design	Qualitative interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data from questionnaires will only be considered if insufficient qualitative evidence is identified
Other inclusion exclusion criteria	Exclusions:  ADHD diagnosis made not using DSM-III/ICD-10 or later versions of these (note that studies evaluating treatments for ADHD in a population of people with autistic spectrum disorder will be included if no formal diagnosis of ADHD has been made using these, but evidence of moderate to severe symptoms of hyperactivity, impulsivity, and/or inattention is demonstrated according to validated symptom questionnaires)
Proposed sensitivity / subgroup analysis, or meta-regression	Not applicable
Selection process –	No duplicate screening was deemed necessary for this question, for

duplicate screening / selection / analysis	<p>more information please see the separate Methods report for this guideline.</p> <p>Appraisal of methodological quality: The methodological quality of each study will be assessed using NGC checklists.</p> <p>Evidence will be analysed using thematic analysis; findings will be presented narratively and diagrammatically where appropriate. Findings will be reported according to GRADE CERQual standards</p> <p>Additional qualitative studies will be added to the review until themes within the analysis become saturated; i.e. studies will only be included if they contribute towards the development of existing themes or to the development of new themes.</p>
Data management (software)	<ul style="list-style-type: none"> <li>• Endnote for bibliography, citations, sifting and reference management</li> </ul>
Information sources – databases and dates	<p>Clinical search databases to be used: Medline, Embase, CINAHL, PsycINFO          Date: All years</p> <p>Health economics search databases to be used: Medline, Embase, NHSEED, HTA          Date: Medline, Embase from 2014          NHSEED, HTA – all years</p> <p>Language: Restrict to English only</p> <p>Supplementary search techniques: backward citation searching</p> <p>Key papers: Not known</p>
Identify if an update	Not an update
Author contacts	<a href="https://www.nice.org.uk/guidance/cg72">https://www.nice.org.uk/guidance/cg72</a>
Highlight if amendment to previous protocol	Not an amendment
Search strategy – for one database	For details please see appendix B
Data collection process – forms / duplicate	A standardised evidence table format will be used, and published as appendix D of the evidence report.
Data items – define all variables to be collected	For details please see evidence tables in Appendix D (clinical evidence tables).
Methods for assessing bias at outcome / study level	The risk of bias across all available evidence was evaluated for each outcome according to GRADE CERQual standards.
Criteria for quantitative synthesis	N/A
Methods for quantitative analysis – combining studies and exploring (in)consistency	N/A
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual and the methods section of this guideline.

Rationale / context – what is known	For details please see the introduction to the evidence review.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Centre (NGC) and chaired by Gillian Baird in line with section 3 of Developing NICE guidelines: the manual. Staff from NGC undertook systematic literature searches, critically appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the evidence review in collaboration with the committee. For details please see Developing NICE guidelines: the manual and the methods section of this guideline.
Sources of funding / support	NGC is funded by NICE and hosted by the Royal College of Physicians.
Name of sponsor	NGC is funded by NICE and hosted by the Royal College of Physicians.
Roles of sponsor	NICE funds NGC to develop guidelines for those working in the NHS, public health and social care in England.
PROSPERO registration number	Not registered

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**Table 18: Health economic review protocol**

<b>Review question</b>	<b>All questions – health economic evidence</b>
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	Populations, interventions and comparators must be as specified in the clinical review protocols in appendix A above. Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) Unpublished reports will not be considered unless submitted as part of a call for evidence. Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter – see appendix B. For questions being updated, the search will be run from December 2007, which was the cut-off date for the searches conducted for NICE guideline CG72
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2001, abstract-only studies and studies from non-OECD countries or the USA will also be excluded. Studies published after 2001 that were included in the previous guideline will be reassessed for inclusion and may be included or selectively excluded based on their relevance to the questions covered in this update and whether more applicable evidence is also identified. Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in appendix H of Developing NICE guidelines: the manual (2014). <sup>142</sup>  Inclusion and exclusion criteria If a study is rated as both ‘Directly applicable’ and with ‘Minor limitations’ then it will be included in the guideline. A health economic evidence table will be completed and it will

Review question	All questions – health economic evidence
	<p>be included in the health economic evidence profile.</p> <p>If a study is rated as either ‘Not applicable’ or with ‘Very serious limitations’ then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile.</p> <p>If a study is rated as ‘Partially applicable’, with ‘Potentially serious limitations’ or both then there is discretion over whether it should be included.</p> <p>Where there is discretion</p> <p>The health economist will make a decision based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded on the basis of applicability or methodological limitations will be listed with explanation as excluded health economic studies in appendix G.</p> <p>The health economist will be guided by the following hierarchies.</p> <p>Setting:</p> <p>UK NHS (most applicable).</p> <p>OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden).</p> <p>OECD countries with predominantly private health insurance systems (for example, Switzerland).</p> <p>Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations.</p> <p>Health economic study type:</p> <p>Cost–utility analysis (most applicable).</p> <p>Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis).</p> <p>Comparative cost analysis.</p> <p>Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.</p> <p>Year of analysis:</p> <p>The more recent the study, the more applicable it will be.</p> <p>Studies published in 2001 or later (including any such studies included in the previous guideline) but that depend on unit costs and resource data entirely or predominantly from before 2001 will be rated as ‘Not applicable’.</p> <p>Studies published before 2001 (including any such studies included in the previous guideline) will be excluded before being assessed for applicability and methodological limitations.</p> <p>Quality and relevance of effectiveness data used in the health economic analysis:</p> <p>The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.</p> <p>Economic evaluations that are based on studies excluded from the clinical review will be excluded.</p>

## Appendix B: Literature search strategies

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual, Oct 2014, updated 2017  
<https://www.nice.org.uk/guidance/pmg20/resources/developing-nice-guidelines-the-manual-pdf-72286708700869>

For more detailed information, please see the Methodology Review.

### B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

**Table 19: Database date parameters and filters used**

Database	Dates searched	Search filter used
Medline (OVID)	1948 – 28 April 2017	Exclusions Patient views/qualitative studies
Embase (OVID)	1974– 28 April 2017	Exclusions Patient views/qualitative studies
CINAHL (EBSCO)	Inception– 28 April 2017	Exclusions Patient views/qualitative studies
PsycINFO (ProQuest)	Inception– 28 April 2017	Exclusions Patient views/qualitative studies

#### Medline (Ovid) search terms

1.	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.

18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	Animals, Laboratory/
23.	exp animal experiment/
24.	exp animal model/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
30.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
31.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
32.	or/29-31
33.	28 and 32

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### Embase (Ovid) search terms

1.	attention deficit disorder/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	case report/ or case study/
14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	nonhuman/
20.	exp Animal Experiment/

21.	exp Experimental Animal/
22.	animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
28.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
29.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
30.	or/27-29
31.	26 and 30

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**CINAHL (EBSCO) search terms**

S1.	(MH "Attention Deficit Hyperactivity Disorder")
S2.	((attenti* or disrupt*) n3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*))
S3.	adhd or addh or ad hd or ad/hd
S4.	attenti* n3 deficit*
S5.	((hyperkin* or hyper kin*) n1 (syndrome* or disorder*)) or hkd)
S6.	(minimal brain n2 (dysfunct* or disorder*))
S7.	S1 OR S2 OR S3 OR S4 OR S5 OR S6
S8.	(MH "Qualitative Studies+")
S9.	(MH "Qualitative Validity+")
S10.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S11.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S12.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S13.	S8 OR S9 OR S10 OR S11 OR S12
S14.	S7 AND S13
S15.	PT anecdote or PT audiovisual or PT bibliography or PT biography or PT book or PT book review or PT brief item or PT cartoon or PT commentary or PT computer program or PT editorial or PT games or PT glossary or PT historical material or PT interview or PT letter or PT listservs or PT masters thesis or PT obituary or PT pamphlet or PT pamphlet chapter or PT pictorial or PT poetry or PT proceedings or PT "questions and answers" or PT response or PT software or PT teaching materials or PT website
S16.	S14 NOT S15 Limiters - English Language; Exclude MEDLINE records

3

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### PsycINFO (ProQuest) search terms

1.	SU.EXACT.EXPLODE("Attention Deficit Disorder") OR TI((attenti* OR disrupt*) NEAR/3 (adolescent* OR adult* OR behav* OR child* OR class OR classes OR classroom* OR condition* OR difficult* OR disorder* OR learn* OR people OR person* OR poor OR problem* OR process* OR youngster*)) OR AB((attenti* OR disrupt*) NEAR/3 disorder*) OR TI,AB(adhd OR addh OR ad-hd OR ad??hd) OR TI,AB(attenti* NEAR/3 deficit*) OR TI,AB(((hyperkin* OR (hyper-kin*)) NEAR/1 (syndrome* OR disorder*)) OR hkd) OR TI,AB(minimal NEAR/1 brain NEAR/2 (dysfunct* OR disorder*))
2.	SU.EXACT("Qualitative Research") OR (SU.EXACT("Narratives") OR SU.EXACT("Interviews")) OR (SU.EXACT("Questionnaires") OR SU.EXACT.EXPLODE("Surveys")) OR (qualitative OR interview*) OR (focus-group* OR theme*) OR (questionnaire* OR survey*) OR (metasynthes* OR meta-synthes*) OR (metasummar* OR meta-summar*) OR (metastud* OR meta-stud*) OR (metathem* OR meta-them*) OR ethno* OR (emic OR etic) OR (phenomenolog* OR "grounded theory") OR (constant-compar* OR thematic* NEAR/3 analys*) OR (theoretical-sampl* OR purposive-sampl*) OR (hermeneutic* OR heidegger*) OR (husserl* OR colaizzi*) OR (van-kaam* OR van-manen*) OR (giorgi* OR glaser*) OR (strauss* OR ricoeur*) OR (spiegelberg* OR merleau*)
3.	1 AND 2
4.	NOT (Dissertations & Theses AND Books)
5.	English

## 2 B.2 Health Economics literature search strategy

3 Health economic evidence was identified by conducting a broad search relating to ADHD  
4 population in NHS Economic Evaluation Database (NHS EED – this ceased to be updated  
5 after March 2015) and the Health Technology Assessment database (HTA) with no date  
6 restrictions. NHS EED and HTA databases are hosted by the Centre for Research and  
7 Dissemination (CRD). Additional searches were run on Medline and Embase.

8 **Table 20: Database date parameters and filters used**

Database	Dates searched	Search filter used
Medline	2014 – 28 April 2017	Exclusions Health economics
Embase	2014 – 28 April 2017	Exclusions Health economics
Centre for Research and Dissemination (CRD)	HTA - 2008 – 28 April 2017 NHSEED - 2008 to March 2015	None

9

10

### Medline (Ovid) search terms

1.	"attention deficit and disruptive behavior disorders"/ or attention deficit disorder with hyperactivity/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*).ti,ab.
8.	or/1-7

9.	limit 8 to English language
10.	letter/
11.	editorial/
12.	news/
13.	exp historical article/
14.	Anecdotes as Topic/
15.	comment/
16.	case report/
17.	(letter or comment*).ti.
18.	or/10-17
19.	randomized controlled trial/ or random*.ti,ab.
20.	18 not 19
21.	animals/ not humans/
22.	Animals, Laboratory/
23.	exp animal experiment/
24.	exp animal model/
25.	exp Rodentia/
26.	(rat or rats or mouse or mice).ti.
27.	or/20-26
28.	9 not 27
29.	Economics/
30.	Value of life/
31.	exp "Costs and Cost Analysis"/
32.	exp Economics, Hospital/
33.	exp Economics, Medical/
34.	Economics, Nursing/
35.	Economics, Pharmaceutical/
36.	exp "Fees and Charges"/
37.	exp Budgets/
38.	budget*.ti,ab.
39.	cost*.ti.
40.	(economic* or pharmaco?economic*).ti.
41.	(price* or pricing*).ti,ab.
42.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
43.	(financ* or fee or fees).ti,ab.
44.	(value adj2 (money or monetary)).ti,ab.
45.	or/29-44
46.	exp models, economic/
47.	*Models, Theoretical/
48.	*Models, Organizational/
49.	markov chains/
50.	monte carlo method/
51.	exp Decision Theory/
52.	(markov* or monte carlo).ti,ab.

53.	econom* model*.ti,ab.
54.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
55.	or/46-54
56.	28 and (45 or 55)

1

2

### Embase (Ovid) search terms

1.	attention deficit disorder/
2.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)).ti.
3.	((attenti* or disrupt*) adj3 disorder*).ab.
4.	(adhd or addh or ad hd or ad??hd).ti,ab.
5.	(attenti* adj3 deficit*).ti,ab.
6.	((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd).ti,ab.
7.	(minimal brain adj2 (dysfunct* or disorder*)).ti,ab.
8.	or/1-7
9.	limit 8 to English language
10.	letter.pt. or letter/
11.	note.pt.
12.	editorial.pt.
13.	case report/ or case study/
14.	(letter or comment*).ti.
15.	or/10-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animal/ not human/
19.	nonhuman/
20.	exp Animal Experiment/
21.	exp Experimental Animal/
22.	animal model/
23.	exp Rodent/
24.	(rat or rats or mouse or mice).ti.
25.	or/17-24
26.	9 not 25
27.	statistical model/
28.	exp economic aspect/
29.	27 and 28
30.	*theoretical model/
31.	*nonbiological model/
32.	stochastic model/
33.	decision theory/
34.	decision tree/
35.	monte carlo method/
36.	(markov* or monte carlo).ti,ab.

37.	econom* model*.ti,ab.
38.	(decision* adj2 (tree* or analy* or model*)).ti,ab.
39.	or/29-38
40.	*health economics/
41.	exp *economic evaluation/
42.	exp *health care cost/
43.	exp *fee/
44.	budget/
45.	funding/
46.	budget*.ti,ab.
47.	cost*.ti.
48.	(economic* or pharmaco?economic*).ti.
49.	(price* or pricing*).ti,ab.
50.	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
51.	(financ* or fee or fees).ti,ab.
52.	(value adj2 (money or monetary)).ti,ab.
53.	or/40-52
54.	26 and (39 or 53)

1

2

#### NHS EED and HTA (CRD) search terms

#1.	MeSH DESCRIPTOR Attention Deficit and Disruptive Behavior Disorders
#2.	MeSH DESCRIPTOR Attention Deficit Disorder with Hyperactivity
#3.	((attenti* or disrupt*) adj3 (adolescent* or adult* or behav* or child* or class or classes or classroom* or condition* or difficult* or disorder* or learn* or people or person* or poor or problem* or process* or youngster*)):TI
#4.	((attenti* or disrupt*) adj3 disorder*)
#5.	((adhd or addh or ad hd or ad??hd))
#6.	((attenti* adj3 deficit*))
#7.	((((hyperkin* or hyper kin*) adj1 (syndrome* or disorder*)) or hkd))
#8.	((minimal brain adj2 (dysfunct* or disorder*)))
#9.	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8
#10.	(#9) IN NHSEED, HTA

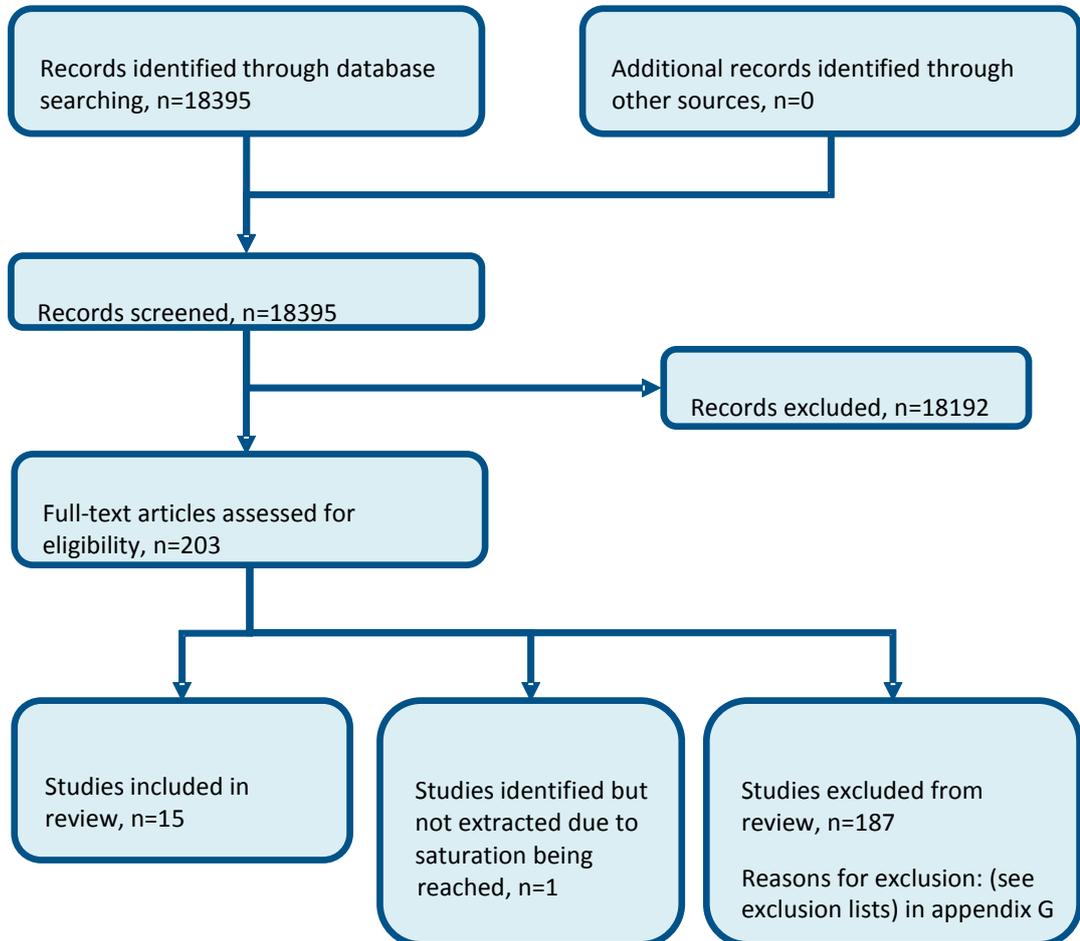
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4

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## Appendix C: Qualitative study selection

Figure 2: Flow chart of clinical article selection for the review of adherence



2

## Appendix D: Qualitative evidence tables

Study (ref id)	Ahmed 2013 <sup>1</sup>
Aim	To explore factors influencing parents' decisions to adhere and persist with ADHD medication
Population	16 parents of children with ADHD (aged 3 to 12 years)
Setting	Australia
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups lasted from 1 to 1.5 hours and were facilitated by a researcher experienced in conducting focus groups. A guide was used to lead discussions. A framework method of analysis was used whereby a thematic framework was developed based on the major themes identified in the dat.
Themes	Parents were concerned about the side effects of medication, and often modified medication doses due to this. Some consulted with HCPs prior to any modifications, whereas others did not. Many parents reported utilising drug holidays to reduce unwanted side effects, without consulting HCPs
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Brinkman 2008 <sup>14</sup>
Aim	To explore how parents make decisions about treatment for their children with ADHD
Population	52 parents of children with ADHD (aged 6 to 17 years)
Setting	USA
Study design	Qualitative (focus groups)
Methods and analysis	12 focus groups with an average length of 1.5 hours. Prompting questions were developed by all investigators and were broad, open ended initially, followed by more specific probing questions to clarify responses and narrow the discussion. Recruitment was terminated when the investigators felt data saturation had been reached. Grounded theory was used for analysis, whereby the investigators read

<b>Study (ref id)</b>	<b>Brinkman 2008<sup>14</sup></b>
	the transcripts, identified emerging themes, and labelled themes to construct a codebook.
Themes	Parents reported that their children sometimes forgot to take their medication
Limitations and applicability of evidence	Minor limitations related to the richness of the data

<b>Study (ref id)</b>	<b>Charach 2006<sup>27</sup></b>
Aim	To explore parents' attitudes towards medicating their child
Population	17 mothers and fathers of 14 children with ADHD (aged 7 to 15 years)
Setting	Canada
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups were led by a social worker and a practical nurse specialist who had worked with the families. A semi-structured guide was used; parents were asked to describe their experiences regarding the use of medication. Data was analysed using thematic analysis. Initially analysed by line by line coding, followed by reviewing of these codes by the whole research team. This was followed by clustering codes into themes that best represented the data set.
Themes	An important aspect of this decision-making was the willingness of the child to take medication. Some children actively fought to not take medication
Limitations and applicability of evidence	Minor limitations related to the richness of the data

Study (ref id)	Charach 2014 <sup>29</sup>
Aim	Exploring adolescents and parents' attitudes towards stimulant treatment
Population	12 children with ADHD (aged 12 to 15 years)
Setting	Canada
Study design	Interviews
Methods and analysis	Semi structured interviews with interview questions, lasting between 60 to 90 minutes. Transcripts were analysed using interpretive interactionist framework
Themes	Some patients continued to adhere to treatment as they got older, as they realised the efficacy of the medication Children stopped medication due to adverse events, insufficient benefit, feeling that the medication changed their sense of self
Limitations and applicability of evidence	Minor limitations related to the role of the researcher and context of the study

Study (ref id)	Coletti 2012 <sup>34</sup>
Aim	To explore parent perspectives on the decision to initiate medication treatment for ADHD
Population	27 parents of children diagnosed with ADHD (aged 5 to 12 years)
Setting	USA
Study design	Qualitative (focus groups)
Methods and analysis	Focus groups were 2 hours in duration and were led by two child psychologists with experience in focus groups. A semi structured guide aided discussions and ensured they were theory driven. An inductive approach was used to analyse transcripts, using grounded theory methods to allow themes to emerge independent of theory.
Themes	Parents that tried to consistently adhere to medicate did so because they felt the improvements extended beyond just ADHD symptoms, and led to

<b>Study (ref id)</b>	<b>Coletti 2012<sup>34</sup></b>
	functional improvements of mood, sleep, and social functioning.
	For some parents, behavioural improvements outweighed side effects, and so they adhered to treatment.
Limitations and applicability of evidence	Minor limitations of the evidence

<b>Study (ref id)</b>	<b>Gallichan 2008<sup>60</sup></b>
Aim	Explore young peoples' perspectives of ADHD
Population	12 young people with ADHD (aged 10 to 17 years)
Setting	UK
Study design	Qualitative (interviews)
Methods and analysis	One on one open-ended interviews ranged from 25 minutes to 1 hour and 15 minutes. Grounded theory was used to analyse the data.
Themes	<p>Young people reported understanding why they needed to take their medication as they got older</p> <p>Children reported attempting to not take their medication and hide this from parents.</p>
Limitations and applicability of evidence	Minor limitations related to the richness of the data

<b>Study (ref id)</b>	<b>Ibrahim 2016<sup>88</sup></b>
Aim	Examine the experiences of drug holidays from caregivers and healthcare professionals
Population	8 GPs, 8 consultants, 5 teachers and 5 mothers (aged children and young people)
Setting	UK
Study design	Interviews
Methods and analysis	Semi-structured interviews were carried out by one author using an interview schedule that focused on descriptions of ADHD and referral and diagnosis processes, and experiences with ADHD. Data was analysed using grounded theory.
Themes	Some parents could cope with their child not taking medication out of school hours, and felt it important to do so. However other parents' were unequipped to do this Young people want to stop their medication to feel like themselves and because they don't feel like the medication is helping
Limitations and applicability of evidence	Minor limitations related to the richness of the data

<b>Study (ref id)</b>	<b>Lefler 2016<sup>111</sup></b>
Aim	To explore the experiences of college students living with ADHD
Population	36 college students with ADHD (aged >18 years)
Setting	USA
Study design	Focus groups
Methods and analysis	8 2 to 2.5 hour focus groups were conducted, each with 4-5 students. A semi-structured interview schedule was used. Focus groups were facilitated by either a clinical psychologist or a student training to be a clinical psychologist. Idiographic inductive analysis was used.

<b>Study (ref id)</b>	<b>Lefler 2016<sup>111</sup></b>
Themes	Students took medication holidays at their own direction, such as on the days that they had classes. Some students reported that they would also use more than was prescribed during periods of deadlines and examinations. They also reported frequently breaking pills up to take smaller doses than prescribed
Limitations and applicability of evidence	Minor limitations of the study related to a lack of context provided

<b>Study (ref id)</b>	<b>Matheson 2013<sup>125</sup></b>
Aim	Explore adults experiences with ADHD
Population	15 adults diagnosed with ADHD in childhood, and 15 diagnosed in adulthood (aged >18 years)
Setting	UK
Study design	Interviews
Methods and analysis	Semi structured face to face interviews were conducted in the participant's home, or at the school of Pharmacy in London. An interview guide was used. Length approximately 1 hour. Thematic analysis used
Themes	<p>Patients reported only taking medication when it was required for work or education purposes</p> <p>Participants reported difficulty in accessing prescriptions, with GPs unwilling to prescribe or pharmacists reluctant to stock or dispense the medication.</p> <p>Participants reported that a lack of cooperation from pharmacists, GPs, and health trusts resulted in periods of cessation, which lasted from days to years. These periods were distressing for patients</p> <p>Many found delays in referral to adult services, discontinuation of support and medication upon turning 18</p> <p>Forgetfulness, side effects, uncertainty of effectiveness and a sense of lost identity were reported as the main reasons for treatment cessation</p>

<b>Study (ref id)</b>	<b>Matheson 2013<sup>125</sup></b>
Limitations and applicability of evidence	Minor limitations related to the richness of the data

<b>Study (ref id)</b>	<b>Meaux 2006<sup>133</sup></b>
Aim	To gain insight about medication use among young people with ADHD
Population	15 college students with ADHD (aged 18+)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured interviews were conducted by the principal investigator. Initial interviews lasted from 1 to 1.5 hours and follow up interviews lasted between 15 to 30 minutes. Content analysis was used to identify raw data clusters within the coded data. Raw data clusters were then combined to form themes
Themes	<p>Students reported they often forgot to take their medication</p> <p>Many students reported not taking their medication on the weekend when they were younger because they didn't want to 'feel like that' over the weekend</p> <p>Students reported that they not only take their medication when they need to, which generally was just when they had a large workload.</p>
Limitations and applicability of evidence	Moderate limitations related to the role of the researcher and the richness of the data

<b>Study (ref id)</b>	<b>Meaux 2009<sup>132</sup></b>
Aim	Explore college students experiences of ADHD
Population	15 college students with ADHD (aged 18 to 21 years)

<b>Study (ref id)</b>	<b>Meaux 2009<sup>132</sup></b>
Setting	USA
Study design	Interviews
Methods and analysis	Semi structured interviews lasting 60 to 90 minutes were conducted. An interview guide was used . Content analysis was used to identify clusters of raw data, which were compared and combined to identify themes. Thematic analysis then allowed for further identification of themes.
Themes	Most participants were not taking their medication on a regular basis as they didn't like how the side effects made them feel.
Limitations and applicability of evidence	Moderate limitations related to the role of the researcher and the richness of the data

<b>Study (ref id)</b>	<b>Mills 2011<sup>135</sup></b>
Aim	To understand how parents decide to medicate their child
Population	19 families (representing 30 children with ADHD) (aged Not specified)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured interviews were conducted. Transcripts were analysed using constant comparative analysis, in order to generate conceptual categories and their properties. Open coding was used initially, followed by axial coding to connect the categories. No further details
Themes	The decision to keep a child on their medication was related mainly to the effectiveness of the treatment.
Limitations and applicability of evidence	Minor limitations related to the context of the study

<b>Study (ref id)</b>	<b>O'Callaghan 2014<sup>144</sup></b>
Aim	To explore the context that influences stimulant medication adherence

<b>Study (ref id)</b>	<b>O'Callaghan 2014<sup>144</sup></b>
Population	18 adults with ADHD (aged >18 years)
Setting	USA
Study design	Interviews
Methods and analysis	Semi-structured telephone interviews lasted an average of 45 minutes. Notes were manually recorded and transcriptions analysed using thematic analysis.
Themes	Participants did not feel equipped to successfully stick to their treatment plan. This was due to being unable to keep monthly appointments for medication management. It seemed that those that benefited more from the treatment were more likely to adhere to it, with benefits clearly outweighing the harm of treatment. Participants reported difficulty getting a prescription refilled due to suspicious questions asked by pharmacists
Limitations and applicability of evidence	Severe limitations relating to the richness of data, data analysis, data collection and the role of the researcher

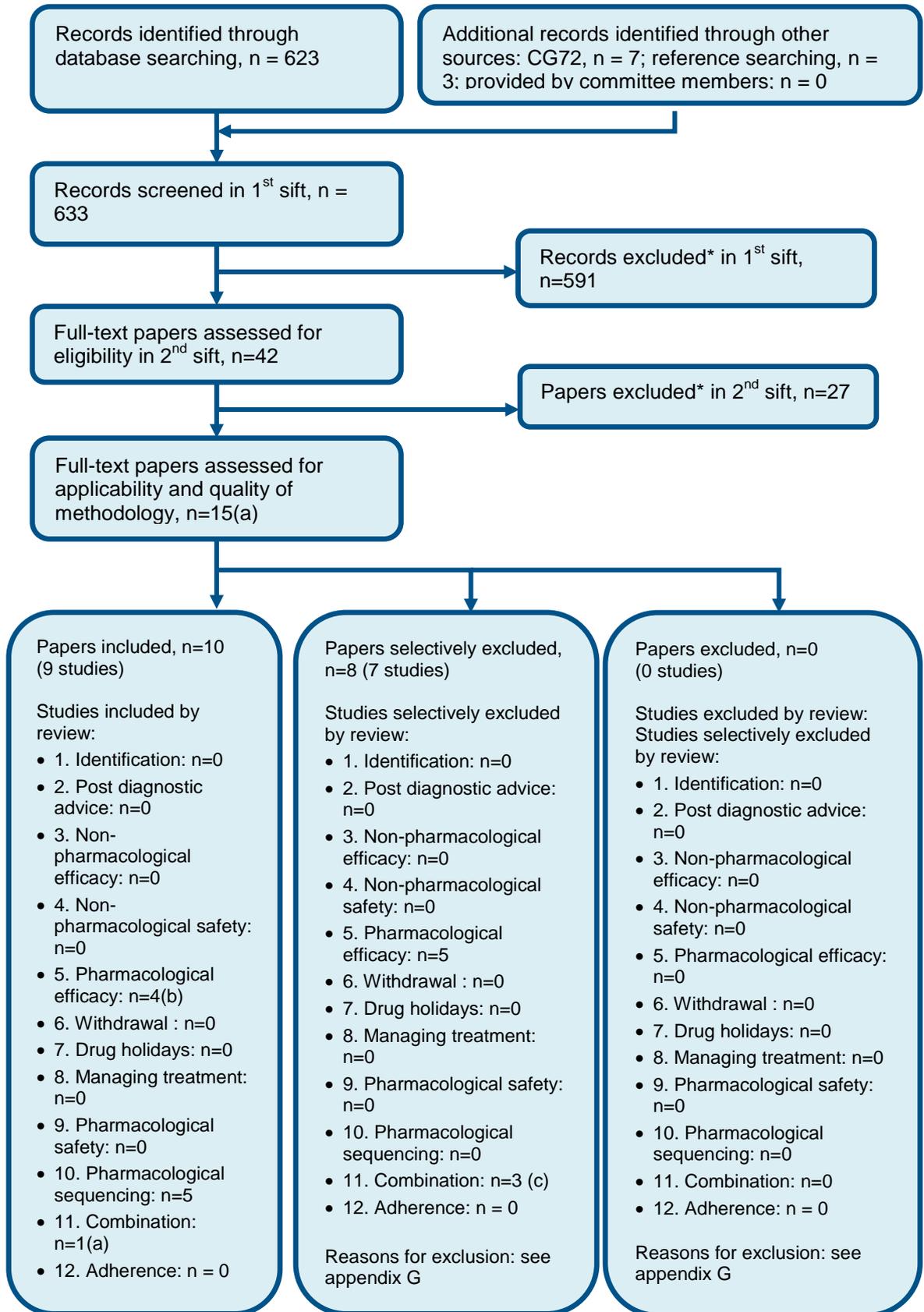
<b>Study (ref id)</b>	<b>Sikirica 2014<sup>164</sup></b>
Aim	To explore the unmet needs of young people with ADHD and their caregivers
Population	38 caregivers (of ages 6 to 17 years) and 28 young people (13 to 17 years) with ADHD took part (aged 6 to 17 years)
Setting	Mixed European countries (including the UK)
Study design	Interviews
Methods and analysis	One to one telephone interviews were conducted by experienced interviewers, who took part in a training seminar including mock interviews. Each interview followed a standardised semi structured interview guide with open ended questions. Interviews with caregivers lasted between 60 to 90 minutes and interviews with young people lasted from 30 to 60 minutes. Thematic analysis was used to identify themes; an initial code system was developed which were organised into themes.
Themes	Participants reported allowing their children to deviate from their treatment and take breaks from their medication.
Limitations and applicability of evidence	Minor limitations related to the richness of the data

<b>Study (ref id)</b>	<b>Smith 2014<sup>171</sup></b>
Aim	Understanding the reasons of low uptake and completion of parent interventions for ADHD
Population	19 practitioners running services for preschool children with ADHD, and 13 parents of children with ADHD (Pre-schoolers)
Setting	UK
Study design	Focus groups
Methods and analysis	semi-structured focus groups using an interview schedule based on themes for a qualitative literature synthesis. Analysed using thematic analysis
Themes	<p>Parents were more likely to drop out if they did not see improvement they expected quickly enough.</p> <p>Many barriers for patients in accessing non-pharmacological treatment were reported by parents and healthcare professionals. Psychological barriers included feelings of shame, embarrassment and fear of being judged. Situational barriers included time commitments, inconvenient session times and location and child care issues. Practitioners also feel that a lack of education, cultural issues, domestic violence and financial difficulties impacted on adherence.</p>
Limitations and applicability of evidence	Minor limitations related to the richness of the data

<b>Study (ref id)</b>	<b>Swift 2013<sup>178</sup></b>
Aim	Patient experiences of ADHD, particularly around transitioning services
Population	10 young adults with ADHD (aged 17-18)
Setting	UK
Study design	Interviews
Methods and analysis	Semi-structured interviews analysed by thematic analysis. Parents were allowed to be present during the interviews. Set questions were used during the interviews, but the format was flexible
Themes	Patients reported that their parents or other family members were often involved in support, helping with medication and clinic

<b>Study (ref id)</b>	<b>Swift 2013<sup>178</sup></b>
	appointments, where some people with ADHD struggle
Limitations and applicability of evidence	Minor limitations related to the richness of the data

1 **Appendix E: Health economic evidence**  
2 **study selection**



\* Non-relevant population, intervention, comparison, design or setting; non-English language

(a) note that there were 2 original models from the previous guideline (either included or excluded) which is why the numbers add to more than 15.

(b) Two articles identified were applicable to Q5 and Q10, for the purposes of this diagram it has been included under Q5 only.

(c) One of these is a model from the previous guideline that was exclude. Two articles identified were applicable to both Q5 and Q11 and have only been included here under Q11. One paper here was selectively excluded in Q11 but included in Q5 and so is double counted in this flowchart.



## Appendix F: **Health economic evidence tables**

None.

# Appendix G: Excluded studies

## G.1 Excluded qualitative studies

**Table 21: Studies excluded from the qualitative review**

Reference	Reason for exclusion
Ahmed 2006 <sup>2</sup>	No relevant themes
Ahmed 2013 <sup>3</sup>	Systematic review
Andrews 2015 <sup>192</sup>	Incorrect study design
Ansari 2016 <sup>4</sup>	Survey
Arango 2013 <sup>5</sup>	Article
Bachman 2000 <sup>6</sup>	Survey
Ball 2001 <sup>7</sup>	Survey
Bartlett 2010 <sup>8</sup>	No relevant themes
Bekle 2004 <sup>9</sup>	Survey
Berger 2008 <sup>10</sup>	Survey
Berger 2015 <sup>11</sup>	No relevant themes
Bringewatt 2013 <sup>12</sup>	No relevant themes
Brinkman 2011 <sup>13</sup>	Literature review
Brinkman 2012 <sup>15</sup>	No relevant themes
Brodin 2008 <sup>16</sup>	No relevant themes
Brook 2000 <sup>18</sup>	Survey
Brook 2005 <sup>17</sup>	Incorrect study design
Brown 2010 <sup>19</sup>	No relevant themes
Bussing 1998 <sup>22</sup>	Survey
Bussing 2012 <sup>20</sup>	Survey
Bussing 2016 <sup>21</sup>	Survey
Butler 2015 <sup>23</sup>	Systematic review
Canela 2017 <sup>24</sup>	No relevant themes
Carpenter-Song 2010 <sup>25</sup>	Article
Carter 2005 <sup>26</sup>	Survey
Charach 2008 <sup>28</sup>	Incorrect study design
Cheung 2015 <sup>30</sup>	No relevant themes
Clarke 2012 <sup>32</sup>	Incorrect study design
Clarke 2013 <sup>31</sup>	Incorrect population
Clay 2008 <sup>33</sup>	Wrong population
Cooper 1998 <sup>35</sup>	No relevant themes
Corcoran 2016 <sup>36</sup>	Systematic review
Cormier 2012 <sup>37</sup>	No relevant themes
Couture 2003 <sup>38</sup>	Questionnaire
Darredeau 2007 <sup>39</sup>	Survey
Davis-Berman 2010 <sup>40</sup>	No relevant themes
Davis-Berman 2012 <sup>41</sup>	No relevant themes
Deane 2012 <sup>42</sup>	Incorrect population
Dennis 2008 <sup>43</sup>	Literature review

Reference	Reason for exclusion
dosReis 2007 <sup>46</sup>	No relevant themes
Dosreis 2008 <sup>47</sup>	Incorrect study design
dosReis 2009 <sup>45</sup>	No relevant themes
dosReis 2010 <sup>44</sup>	No relevant themes
Edwards 2013 <sup>48</sup>	Wrong population
Einarsdottir 2008 <sup>49</sup>	No relevant themes
Eisenberg 2007 <sup>50</sup>	Survey
Elias 2017 <sup>51</sup>	Incorrect population
Emilsson 2016 <sup>52</sup>	Survey
Faber 2006 <sup>53</sup>	Incorrect study design
Fiks 2010 <sup>54</sup>	No relevant themes
Firmin 2009 <sup>55</sup>	No relevant themes
Flannagan 2002 <sup>56</sup>	No relevant themes
Fleishcman 2013 <sup>57</sup>	Survey
Frank 2015 <sup>58</sup>	Incorrect study design
Friars 2009 <sup>59</sup>	No relevant themes
Garro 2009 <sup>61</sup>	Article
Gau 2009 <sup>62</sup>	Incorrect study design
Gerdes 2014 <sup>63</sup>	Incorrect study design - questionnaire
Ghanizadeh 2010 <sup>64</sup>	Questionnaire
Ghosh 2016 <sup>65</sup>	No relevant themes
Ginsberg 2008 <sup>66</sup>	Incorrect study design
Goodwillie 2014 <sup>67</sup>	No relevant themes
Gwernan-Jones 2015 <sup>69</sup>	Literature review
Gwernan-Jones 2016 <sup>68</sup>	Systematic review
Hack 2001 <sup>70</sup>	Incorrect study design
Hallberg 2008 <sup>71</sup>	No relevant themes
Hallerod 2015 <sup>73</sup>	No relevant themes
Hansen 2006 <sup>72</sup>	No relevant themes
Harazni 2016 <sup>74</sup>	No relevant themes
Harvey 2009 <sup>76</sup>	Wrong population, incorrect study design
Hassink-Franke 2016 <sup>77</sup>	No relevant themes
Hazell 2004 <sup>78</sup>	No qualitative results reported
Hebert 2013 <sup>79</sup>	Survey
Henry 2011 <sup>80</sup>	No relevant themes
Hill 2016 <sup>81</sup>	Survey
Ho 2011 <sup>189</sup>	No relevant themes
Hong 2008 <sup>83</sup>	No relevant themes
Honkasilta 2014 <sup>84</sup>	No relevant themes
Honkasilta 2016 <sup>85</sup>	No relevant themes
Hughes 2007 <sup>86</sup>	No relevant themes
Hughes 2009 <sup>87</sup>	No relevant themes
Ide-Okochi 1016 <sup>89</sup>	Article
Jackson 2008 <sup>90</sup>	No relevant themes
Kean 2005 <sup>91</sup>	Incorrect study design

Reference	Reason for exclusion
Kendall 1997 <sup>92</sup>	Incorrect study design
Kendall 2003 <sup>93</sup>	No relevant themes
Kendall 2016 <sup>94</sup>	No relevant themes
Kildea 2011 <sup>95</sup>	No relevant themes
King 2016 <sup>96</sup>	Wrong population
Kisely <sup>97</sup>	Survey
Klasen <sup>98</sup>	No relevant themes
Knipp <sup>99</sup>	No relevant themes
Ko <sup>100</sup>	Questionnaire
Koerting <sup>101</sup>	Review
Kollins <sup>102</sup>	Review
Kovshoff <sup>104</sup>	No relevant themes
Kronenberg <sup>105</sup>	Incorrect population
Kutuk 2016 <sup>106</sup>	Survey
Larson <sup>107</sup>	No relevant themes
Laugesen <sup>108</sup>	Unable to access
Laugesen <sup>108</sup>	Systematic review
Lee <sup>109</sup>	No relevant themes
Lee <sup>110</sup>	No relevant themes
Leggett <sup>112</sup>	No relevant themes
Leslie <sup>113</sup>	No relevant themes
Lewis 2016 <sup>116</sup>	Erratum
Lewis-Morton <sup>114</sup>	No relevant themes
Liebrez 2016 <sup>117</sup>	No relevant themes
Lin <sup>118</sup>	No relevant themes
Ljusberg <sup>119</sup>	No relevant themes
Loe <sup>120</sup>	No relevant themes
Lopes <sup>121</sup>	Incorrect population
Maassen <sup>122</sup>	No relevant themes
Marcer <sup>123</sup>	Questionnaire
Mathers <sup>124</sup>	Incorrect study design
Matthys <sup>126</sup>	No relevant themes
McCarthy <sup>127</sup>	Survey
McGoron <sup>128</sup>	Questionnaire
McIntrye <sup>129</sup>	No relevant themes
McKay <sup>130</sup>	Wrong population
McMenamy <sup>131</sup>	Wrong population
Michielsen <sup>134</sup>	Wrong population
Mills <sup>103</sup>	Abstract
Moen <sup>136</sup>	No relevant themes
Morsink 2017 <sup>137</sup>	No relevant themes
Muhlbacher <sup>138</sup>	Abstract
Muhlbacher <sup>138</sup>	Abstract
Murrell <sup>139</sup>	Incorrect study design
Mychailyszyn <sup>140</sup>	No relevant themes

Reference	Reason for exclusion
Myers <sup>141</sup>	Incorrect study design
Nehlin <sup>143</sup>	No relevant themes
Olaniyan <sup>145</sup>	No relevant themes
Oruche <sup>146</sup>	Wrong population
Perry <sup>147</sup>	No relevant themes
Ramsay <sup>148</sup>	Incorrect study design
Raskind <sup>149</sup>	Survey
Reale <sup>150</sup>	Survey
Reid <sup>151</sup>	No relevant themes
Rogalin <sup>152</sup>	No relevant themes
Russell <sup>153</sup>	No relevant themes
Salt <sup>154</sup>	No relevant themes
Sandler <sup>155</sup>	No relevant themes
Schatz <sup>156</sup>	Systematic review
Schreuer 2017 <sup>157</sup>	No relevant themes
Schrevel <sup>158</sup>	No relevant themes
Schrevel <sup>158</sup>	No relevant themes
Schubert <sup>159</sup>	No relevant themes
Segal <sup>160</sup>	No relevant themes
Segal <sup>161</sup>	No relevant themes
Shattell <sup>162</sup>	No relevant themes
Shaw <sup>163</sup>	No relevant themes
Simons <sup>165</sup>	No relevant themes
Singh <sup>167</sup>	Article
Singh <sup>166</sup>	No relevant themes
Singh <sup>168</sup>	Article
Singh <sup>169</sup>	Article
Sleath 2016 <sup>170</sup>	Survey
Soderqvist 2017 <sup>172</sup>	No relevant themes
Solberg <sup>173</sup>	Incorrect study design - questionnaire
Sox <sup>174</sup>	Incorrect study design
Srignanasoundari 2017 <sup>175</sup>	No relevant themes
Stroh <sup>176</sup>	Survey
Surman <sup>177</sup>	Incorrect study design
Tatlow-Golden 2016 <sup>179</sup>	Systematic review
Taylor <sup>181</sup>	No relevant themes
Taylor 2015 <sup>180 180</sup>	No relevant themes
Thiruchelvam <sup>182</sup>	Incorrect study design
Travell <sup>183</sup>	Analysis
Varley <sup>184</sup>	Article
Waite <sup>185</sup>	No relevant themes
Wallace <sup>186</sup>	No relevant themes
Wan 2016 <sup>187</sup>	No relevant themes
Wiener <sup>188</sup>	No relevant themes
Wilkes-Gillan <sup>82</sup>	No relevant themes (parental intervention)

Reference	Reason for exclusion
Wilkinson <sup>190</sup>	No relevant themes
Williams <sup>191</sup>	No relevant themes
Williamson <sup>193</sup>	Incorrect study design
Winter <sup>194</sup>	Incorrect study design
Wolpert <sup>75</sup>	No relevant themes
Wright <sup>195</sup>	No relevant themes
Young <sup>197</sup>	No relevant themes
Young <sup>196</sup>	No relevant themes
Young <sup>198</sup>	No relevant themes
Zhang 1017 <sup>199</sup>	No relevant themes

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**Table 22: Studies identified but not included in the qualitative review due to saturation being reached**

Reference
Lewis 2016 <sup>115</sup>

5

## **G.2 Excluded health economic studies**

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None.